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# The phenomenological experience of dementia and user interface development

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*Abstract*— **This study follows ISISEMD through a phenomenological approach of investigating the experience of the Human Computer Interaction (HCI) for someone with dementia. The aim is to accentuate the Assistive Technology (AT) from the end user perspective. This paper supports that older adults and those with dementia should no longer be an overlooked population and how the HCI community can learn from their experiences to develop methods and design interfaces which truly benefit their target population. Guidelines from previous research are incorporated along with eclectic, user-centered strategies as the interface designers for project ISISEMD develop appropriate and effective modalities.**

***Keywords - Assistive Technology, phenomenology, Human Computer Interaction, computer interface, dementia***

## I. INTRODUCTION

It is well known that older adults, on average, have significantly less computer experience [1], yet this should not exclude them from creating an active role in shaping user interface intended directly for their cohort. Researchers and developers will gain the most benefit from studying and observing how the elderly currently interact with computers and the reasons why they choose to do so or not. Studies are showing that the rate and increase of computer use by older adults is growing [1-4], and, furthermore, that they are motivated to learn and apply computer skills [1][5]. Collaboration with older adults with dementia is particularly challenging when it comes to computer interface design [6], but and research and application in this area is timely and mandatory [4]. Dementia can occur in anyone, at any age, resulting from injury or disease, although it is most commonly associated with aging [7]. Dementia is not a specific disorder or disease, but a syndrome (group of symptoms) associated with a progressive loss of memory and other intellectual functions that is serious enough to interfere with performing the tasks of daily life. It consists of an overall decline in intellectual function, including difficulties with language, simple calculations, planning, judgment, and motor skills as well as a gradual loss of memory [7]. For these reasons alone, adults with dementia require assistance in maintaining their daily life, and here is where technology strives help them while also enhancing their sense of autonomy.

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Assistive devices and ambient technologies are implemented and utilized by older populations to enhance intact functioning, accommodate the level of decreasing functioning, and allow individuals to live in their own community safely. The development and implementation of Assistive Technologies (AT) for home care is becoming more commonplace in industrialized societies, and the further specification of AT towards dementia therapy and care is fueled by societal and ethical considerations of the large numbers of older adults being diagnosed and projected to live with cognitive impairments in coming years [6]. To truly provide a service to aging adults and those with chronic syndromes, investigation into the individual experience is imperative in order to provide appropriate, effective, efficient, and high quality care.

Phenomenology explores the fundamental nature of objects or occurrences as they present themselves in human consciousness [8]. It studies how things are perceived (as opposed to how things are); the description of conscious experience without allusion to the question of whether what is experienced is objectively real. This means that we do not experience a technological artifact, whether it be a PDA or electric tea kettle, solely stipulated by its predetermined design (e.g. mass and objectives), but also by its functionality and significance. The founder of phenomenology, Husserl [9], proposed that other disciplines might develop from this philosophy as a way of better understanding the objectives with which they deal. The movement towards the application of phenomenological study is principally due to researchers seeking to understand the intricacies of individual experience [8]. This is quite applicable to dementia, as the perceptions of the individual are often different than what may be perceived by individuals without dementia. Research in this area will be more successful when scientists start working with the understanding that it is the individual perception, regardless if it is considered accurate or not, that makes a difference in individual user acceptance.

The ISISEMD consortium [10] works in this direction, with a main goal to measure quality of life outcomes in aging adults with dementia when provided innovative services which can support their unmet needs. The ISISEMD system uses a number of deferent technologies, some of them requiring user interaction. Striving to not only impact a large minority in health care, the consortium is also merging the boundaries between engineering sciences, social sciences, health care,

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business and marketing, by exploring the individual user experience to ensure the success of the project.

## II. DEVELOPMENT METHODOLOGY

Participatory design techniques actively collaborate with end users throughout the design process. A user sensitive inclusive design, recently put forth by researchers as the University of Dundee, addresses an array of attribute typical of people with dementia to improve customized, adaptive interfaces [11]. However, as each person with dementia is individualistic, each study dealing with the population is subject to idiosyncratic reformulations and alterations. Even traditional user-centered design methods did not provide the greatest understanding of designing for the inexperienced, cognitively impaired, older adult. Traditionally, design practices have used data and technique as their means to acquire user requirements, rather than using the design theory to permit end users to express themselves, encounter issues, and stimulate innovation [6][8]. Working by the latter approach allows for the significance of the interaction to modify not only the design, but the value of what is produced. ISISEMD is not following one particular methodology, but rather incorporating assorted theory and style to accommodate its own eclectic approach. It is believed that this will allow for more adaptability during all project phases as well as cultivate more feasible, reliable outcomes.

### *A. Lessons from the literature*

Unfortunately, when it comes to older adults' computer usage, they fall into the digital divide, those with dementia certainly fall into the disability gap as well. Because technological advances are rapidly occurring, the gap is widening and significant endeavors are required in order to keep this consumer group involved in the market. Cook [12] highlights that there are two important lines of attack:

1. To make conventional technology approachable and manageable to those with disabilities, or
2. Design technologies expressly for this target group.

The first method is known as universal design, and strives to include all users regardless of disadvantage; the second is adapted for assistive technologies and is more likely to be developed through user-centric methodologies [13].

The number of older adults becoming computer savvy and the growing adaptability of electronic technologies have reached a point where they can unite and work better together than separately. Although the use of technologies to develop non-pharmacological interventions for dementia care is a comparably new sphere of exploration, the wealth of information in all applicable domains is continuing to expand and ready to be applied. Previously, older adults, especially individuals with dementia, had been disregarded as secondary consumers of technology applications [3]. Only recently have systems been designed and marketed towards aging adults, and even more recently has the scientific community integrated this consumer group in their development methodology [14]. Rather than focusing on intended, static solutions, researchers and developers in ISISEMD are pushing to create flexible opportunities for innovation with intent. They are setting the parameters for development to fall within, while letting the entire process dictate the direction of product evolution. Agreeing with Astell [6], the developments obligate an understanding of the difficulties in addition to a comprehension of their influence, to be conscious of the implications of practical application and the resulting benefits, rather than unconsciously developing for the sake of new technology. Design methodology will investigate user requirements and consumer needs in order to generate a design that satisfies the functions of intended use.

Morris [15] found that participants experienced technology both rationally and existentially, meaning that they experienced it could contribute in either a singular, compound manner or collectively to support their recognition and representation of self. Using cues that are recognizable and easy to interpret will decrease the confusion that often results from abstract thinking in people with dementia [3][16]. The interface design should facilitate direction from one point to the next without the need for foresight or increased logical deduction on part of the end user.

Other European projects (Technology, Ethics, and Dementia Report [17]; ASTRID Report [18]; At Home with AT [19]; ENABLE Project [20]) have stated requirements for technology for people with dementia:

- Support the user's sense of autonomy
- Support decision-making
- Be a positive influence on the user's quality of life
- Support intact abilities while de-emphasizing a loss of function
- Support the end user's image of themselves as a person with abilities, not reinforce a disabled mentality
- Provide effective information that is visible and available
- Provide autonomous systems that require a minimum of learning and interaction with new information
- Audio/visual multimedia [21]
- Simple language
- Large font to balance macular degeneration
- Choice of colors to prevent glare

ISISEMD is aiming to adjust the personal environment to agree with intact functioning at the degree of impairment. Assistive devices and ambient technologies are implemented and utilized by older populations to enhance intact functioning, accommodate the level of decreasing functioning, and allow individuals to live in their own community safely. In various respects, the living environment is of utmost and personal importance; as life beyond the home becomes increasingly challenging, the surroundings contract and become more personalized, either enabling or hindering opportunities for a person to maintain and express aspects of their identity.

### *B. Population analysis*

#### *1) Aging adults with dementia*

Older adults reserve the knowledge of all the ages of their and do not integrate their aging into their own context the way an observer may [8]. Persons with dementia are even more dependent on context as it changes form as experience and reflection are linked through new interactions. Their personalities have not disappeared, even if they may no longer

express them as openly as they used to. Being conscious of this allows researchers to understand the phenomenological experience of dementia and the uniqueness of individual experience. When the phenomenological perception is affirmed, the individual is validated. Design solutions should now be shaped by the physical and phenomenological experiences of the end user; by better understanding the phenomenological experiences of older adults with dementia, a better solution can be developed.

The previous lack of older adults' computer usage is not due to the complexity of the technologies, but to the interactions with the technology itself and the limitations of the aging body, particularly cognition in those with dementia. Most research on HCI with aging adults has been directed towards exploring only physical changes associated with aging, such as sensory decline [14], as the ageing process affects the ability to interact with a standard user interface. However, research is revealing that older adults desire to be involved in the Internet age and use computers but are deterred when they experience difficulties in learning new technologies [1][5]. Studies are also showing that this deterrence can be subdued through direct experience and familiarity [5][22]. Having lower technology experience will not necessarily mean older adults with dementia cannot become competent computer users; the majority of computer users begin with low capabilities and develop their skills through experience.

In addition to the limitations which ageing has with respect to the use of new technologies, persons with dementia have additional needs in their everyday functioning. In order to create an interface design that will fit end users' needs, Nygård [23] explains how people with dementia are conscious of their preferences, even if they may not be capable of describing or reflecting on them, and actively apply them to their choices. By recognizing their motivations, conceptualization, perceptions, and employed coping strategies, we have useful information to ascertain individual needs. Morris [15] validates that participants develop their own methods of interacting, illustrated through the account of one woman with dementia who would print a blank page from her printer each morning in order to keep track of the date. This was not the intended use for installing an intricate system in her home, but such demonstrations epitomize how people with dementia can come up with innovative methods to make use of their environment for support.

Additionally, end users will most likely require additional training and support than is first anticipated, and prior technology experience will not a reliable predictor for the level of support required [1]. With the understanding that technology is contextual, it is essential that the artifacts are integrated into daily routines and cater to personal interests. Successful integration would mean that the technology becomes consciously inseparable from carrying out daily habits and activities.

*2) ISISEMD participants*

ISISEMD participants will include not only the older adults with dementia, but their primary caregivers, and professional care team (i.e. neurologists, general practitioners, and home care staff etc. who regularly interact with the patient) as all will be utilizing ISISEMD services and interacting with implemented technologies. The pilot trials will be a controlled study, under real-life conditions in the home environment, for a period of 12 months in four different European countries – Denmark, Greece, Finland, and North Ireland. After approval from regional ethical committees, the pilot participants will be recruited based on specific inclusion/exclusion criteria. The main inclusion criterion is based on older adults with cognitive impairments or mild dementia, who live in their own dwelling in the community, and agree to utilize assistive technologies in clinical trials**.** The additional characteristics are summarized in Table 1.

Table 1: Characteristics of pilot site participants

| **Characteristics** | **Profile of primary end user population** |
|---|---|
| Gender | Both genders; preferably 50% split |
| Age | 60-90 years old |
| Health needs | May have other chronic disease or ailments |
| Care needs | - General needs of older adults<br>- Dementia<br>Care needs<br>• self-care<br>• medication management<br>• nutrition and hydration management<br>• activity reminders<br>• safety in the home<br>• social needs |
| Needed service/ technology | - Self-care<br>- Home safety<br>- Cognitive training<br>- Medication management<br>- Communication with caregivers<br>- Social interaction |
| Experience with technology | In most cases<br>• Not experienced with everyday communication via internet<br>• Limited or no computer literacy<br>• Lack of interaction with mobile phones |

*C. Interaction with end users*

The technology services ISISEMD provides can only partially address these unmet needs. Examples of needs that will be addressed are:

- assistance in setting and maintaining structure of the day, sometimes through diverse prompts (i.e. eating meals, drinking water, medical appointments, taking medication, social engagements, etc.);
- needs for safe living in home environment (i.e. notification if kitchen equipment is left on past pre-determined time,

notification if the person with dementia leaves the house, as well as locating assistance, etc.);

- needs to enhance memory functions (i.e. through interactive reminisce therapy devices, multimedia cognitive stimulation therapy, etc.);
- the need to easily communicate with their closest relatives and formal caregivers, especially in the event of a critical situation such as finding themselves lost; and
- lifestyle and pattern observation through various sensing systems (i.e. sensors under the mattress to alert caregivers when someone gets out of bed in the night, systems that alert if a person behaves outside their normal, pre-determined parameters, etc.), which can aid in early detection of a change in condition or for the revision of intervention therapies.

For the whole range of ISISEMD home services to be offered by the system, only some of them require user interaction, and those are incorporating a PC touch screen. Value added services, such as cognitive stimulation, non-failure reminisce activities, and support for social integration, the aging adult with dementia will be relating directly to the AT devices. Additionally, the partners are aware of interconnected difficulties and hindrances, associated with the characteristics of the pilot site populations:

- Conditions that interfere with the use of technology – every person with dementia has individualistic symptoms which develop in a "personalized" way depending on the stage of decline, gender, mentality, hobbies, level of education, etc. This means that each person will have personalized needs to be addressed.
- Deficiencies in knowledge about the technology – in general, the older adults in the pilot regions are not especially accustomed to computers. This can serve as a precursor for difficulties in communication between users and their technology.
- The learning time is expected to be longer than with healthy older adults.
- Limitations in the use of instructions.
- The earlier the technology is introduced, the more likely it is to be received and exploited.
- Gradually introduction of the services will be the most accepted.
- The caregiver will most likely need to remind the client to use the technology in the first days.

ISISEMD partners plan to investigate the development of a unified methodology that combines the participatory and sensitive inclusion design approaches from HCI with the person-centered support from dementia research to develop and validate design techniques with and for people with dementia. The project aims to work with people themselves to identify what aspects of computer interface design may act as a barrier to access, and to establish new ways to design computer interfaces. To reach final design on intuitive, easy to use services, ISISEMD follows the considerations in Table 2.

ISISEMD partners are aware that trial participants will require sensitive training and reinforcement to ensure that technologies and services are utilized and accepted. To alleviate this demand, users will be given personal instructions on how to interact with the equipment, direct training guides, and full technical support from ISISEMD partners.

Table 2: Design considerations

| Parameters | Design considerations |
|---|---|
| Presentation of information | • Grouped into meaningful categories<br>• Concentrated in the center<br>• Important information is highlighted |
| Screen layout | • Colored text on colored background avoided<br>• Extra and bold search cues<br>• Explanatory pictures or simple clips when appropriate |
| Navigation and hierarchy | • Shallow hierarchy<br>• Large targets<br>• Fewer choices for the user<br>• No pull down menus<br>• Links clearly named in a bulleted list |
| Instructions | • Language is plain, unambiguous, and consistent |

ISISEMD is additionally planning specific strategies to determine previous experiences with technology, in which forms, and how useful the consumer (i.e. primary end user with dementia, informal caregivers, and professional caregivers) found them to be. Even more so, ISISEMD researchers will evaluate the technology offered, user acceptance, user satisfaction, impact on caregiver burden, and quality of life outcomes.

## III. Discussion and Conclusion

Computer hardware and software programs, combined with user-friendly interfaces and personalization allow interventions to be uniquely appropriate for persons with dementia. Computers present a standardized environment for repeated exercise and databases can easily analyze responses across tasks and sessions, directly enhancing the attaining and retaining of knowledge and ability. This also presents an opportunity to assess a range of intervention or interaction levels to determine their effect on care outcomes [4].

ISISEMD considers each user's own perception of how to interact with assistive technologies; through the empowerment of aged adults with dementia, they are recognized as valuable contributors to their own lives as well as to the scientific community and much beyond. This growing cohort will gain a more powerful voice and play an active role in shaping the future of technology applications. As a beginning step in this

direction, the ISISEMD project will offer innovative services with assistive technologies to the growing number of older adults with dementia, their informal caregivers to reduce their burden, and to formal caregivers to allow for more efficient care provision. These are the focal points considered in ISISEMD methodology, which incorporates the phenomenological experience of dementia in the user interface design.

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